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Responders and non-responders in a study on medical end-of-life decisions in Denmark, the Netherlands, Sweden and Switzerland

Fischer, Susanne ; Miccinesi, Guido ; Hornung, Rainer ; Bosshard, Georg ; Deliens, Luc ; van der Heide, A ; Nilstun, Tore ; Norup, Michael ; Onwuteaka-Philipsen, Bregje D

Abstract: Objectives: To determine the direction and magnitude of participation bias in end-of-life research. Methods: Within the framework of a European survey on medical end-of-life decisions, a non-response study was conducted among physicians in Denmark, the Netherlands, Sweden and Switzerland. People were asked about their attitudes and experiences in the area of medical end-of-life decision. The response rates ranged from 12.8% (Netherlands) to 39.4% (Switzerland). The responders (n = 5 403) and the non-responders (n = 866) were compared regarding socio-demographic characteristics, experiences with terminal patients and agreement with attitudes towards "end-of-life decisions". The reasons for non-participation to the study were analyzed. Results: Non-response did not cause socio-demographic distortion, but non-responders had statistically significantly fewer terminal patients than responders. Agreement rates were statistically significantly higher among responders than among non-responders for euthanasia, non-treatment decision and life-preserving statements. Neutral answers were statistically significantly more frequent among non-responders than among responders for life-preserving and euthanasia statements. The most commonly mentioned reason for non-participation was "lack of time". Conclusion: Non-participation does cause an overestimation of proponents of life-shortening, as well as of life-preserving end-of-life decisions. Non-responders more often have ambiguous attitudes towards end-of-life decisions than responders

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On behalf of the EURELD consortium

Responders and non-responders in a study on medical end-of-life decisions in Denmark, the Netherlands, Sweden and Switzerland

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Summary

Objectives: To determine the direction and magnitude of participation bias in end-of-life research.

Methods: Within the framework of a European survey on medical end-of-life decisions, a non-response study was conducted among physicians in Denmark, the Netherlands, Sweden and Switzerland. People were asked about their attitudes and experiences in the area of medical end-of-life decision. The response rates ranged from 12.8 % (Netherlands) to 39.4 % (Switzerland). The responders ($n = 5403$) and the non-responders ($n = 866$) were compared regarding socio-demographic characteristics, experiences with terminal patients and agreement with attitudes towards "end-of-life decisions". The reasons for non-participation to the study were analyzed.

Results: Non-response did not cause socio-demographic distortion, but non-responders had statistically significantly fewer terminal patients than responders. Agreement rates were statistically significantly higher among responders than among non-responders for euthanasia, non-treatment decision and life-preserving statements. Neutral answers were statistically significantly more frequent among non-responders than among responders for life-preserving and euthanasia statements. The most commonly mentioned reason for non-participation was "lack of time".

Conclusion: Non-participation does cause an overestimation of proponents of life-shortening, as well as of life-preserving end-of-life decisions. Non-responders more often have ambiguous attitudes towards end-of-life decisions than responders.

Keywords: Non-responder study – Physicians – End-of-life decisions – Euthanasia – Non-treatment.

Studies based on surveys include the risk of systematic differences between responders and non-responders. This risk may be especially pronounced when the response rate is low. However, a low response rate does not necessarily mean that the results are biased. Non-response bias occurs when differences in outcome variables exist between responders and non-responders. It has been recommended to counteract this bias by carrying out non-responder studies: A survey of the non-responders of the main study should reveal possible systematic differences between responders and non-responders (e. g. Boersma et al. 1997; Reijneveld & Stronks 1999).

Medical end-of-life decisions with a possible or certain life-shortening effect (ELDs) are an especially sensitive topic. For a long time research was scarce in this field. However, in recent years several studies were conducted quantifying attitudes and practices concerning ELDs (Cohen et al. 1994; Deliens et al. 2000; Di Mola et al. 1996; Peretti-Watel et al. 2003; Willems et al. 2000). Because proponents and opponents of euthanasia or physician-assisted suicide may not answer with a similar frequency, the risk of non-response bias could be particularly high in ELD-studies. Depending on the study design and on the wording of the questions, both an over-representation of proponents and of opponents could be the consequence.

Up to now, as far as we know, no research has been conducted specifically to determine the direction and magnitude of participation bias in end-of-life research. For other sensitive issues (e. g. sexual behaviour, alcohol consumption) it has been shown that non-participation may result in overestimation (Catania et al. 1990; Strassberg & Lowe 1995) or in underestimation (Rogers & Turner 1991) of the actual levels of the investigated behaviour. Some studies did not reveal any differences between responders and non-responders (Big-

gar & Melbye 1992). In the field of sex research it has been shown that experiences with and the meaning of the investigated behavior influences participation. An overestimation of sexual behavior is reported because “non-responders have less sexual experience (...) and therefore may be sexually more inhibited than responders” (Catania et al. 1990; Strassberg & Lowe 1995) and because men with strong machismo values are more likely to participate in such studies. A study in the field of alcohol research shows that non-participation could lead to an underestimation of alcohol consumption, as excessive drinkers and problem drinkers are difficult to reach because of their lifestyle characteristics (Lahaut et al. 2002). In the field of end-of-life research a non-response study has been conducted to find indications for differences in attitudes towards end-of-life decisions between responders and non-responders, by investigating the reasons for non-participation (Onwuteaka-Philipsen et al. 1997). As the main reason for not participating was “shortage of time”, the researchers concluded that no indications were found that attitudes towards end-of-life decisions were the reason for non-participation.

Analysis of non-response is usually limited to comparison of demographic characteristics. For sensitive issues it is found that non-responders are more likely to be male, older, live in cities and have lower educational attainment than responders (e.g. Michael et al. 1994; Sundet et al. 1992). If such differences between responders and non-responders are known, statistical weighting techniques can be applied to minimize biases. However, this approach is far from adequate. Unmeasured variables (such as experiences in end-of-life care) may influence willingness to participate.

The present article describes the results of a non-responder study conducted within an international “medical end-of-life decision study” (van der Heide et al. 2003; Miccinesi et al. 2005), in which physicians were asked questions about their attitudes and experiences in this area. First we address the question of whether there are differences between the participants in the main study and the non-responders, regarding demographic characteristics and the number of terminal patients they usually care for. Secondly, the reasons for non-participation in the main study are considered. Finally, we want to obtain evidence of whether attitudes towards end-of-life decisions between non-responders and responders differ, and if so, how.

Methods

Main study

Design: An 8-page written questionnaire with structured questions was sent to practising physicians in six European countries, namely Belgium (Flanders), Denmark, Italy (areas:

Emilia-Romagna, Trento, Tuscany and Veneto), the Netherlands, Sweden and Switzerland. In the following study, only data from the four countries which participated in the non-responder study (Denmark, the Netherlands, Sweden and Switzerland) are reported.

Population: Physicians from ten specialties were asked to participate: anaesthesiology, general practice, geriatrics, gynaecology, internal medicine, neurology, nursing home medicine (only in the Netherlands), oncology (not a registered separate specialty in the Netherlands), pulmonology and surgery. In each country, for each specialty a random sample of 300 physicians was drawn from the professional registers. When there were less than 300 physicians working in a specialty, all specialists were included in the sample. The response rates for physicians who could be tracked were as follows: Denmark 69 % (n = 1 284), the Netherlands 58 % (n = 1 390), Sweden 62 % (n = 1 646) and Switzerland 65 % (n = 1 449). Of these physicians, 5 % (n = 67) in Denmark, 8 % (n = 115) in the Netherlands, 8 % (n = 132) in Sweden and 3.6 % (n = 52) in Switzerland indicated that they are not currently working and were excluded from the analysis. In all countries, the data-collection procedure precluded linking information from the questionnaire to individual doctors.

Measurement instrument: The questionnaire for the main study consisted of pre-structured questions. A common English version was translated into the languages of the countries and translated back into English to search for inconsistencies. Besides questions on background characteristics (age, sex, religion, specialty, workplace) questions were asked about intended behaviour, attitudes and experiences relating to end-of-life care.

End-of-life decisions included:

- withholding or withdrawing treatment, taking into account the probability or certainty that this would hasten the end of the patient’s life
- intensifying the alleviation of pain and/or symptoms by using drugs such as opioids, taking into account the probability or certainty that this would hasten the end of the patient’s life
- administering drugs with the explicit intention of hastening the end of the patient’s life (with or without an explicit request of the patient)
- prescribing or supplying drugs on the explicit request of a patient with the explicit intention of hastening the end of life

Non-responder study

Procedure: Within the framework of the main study, in four of the six countries (Denmark, the Netherlands, Sweden and Switzerland) a non-responder study was conducted. A one-page written questionnaire with structured questions was sent to physicians.

Population: All physicians who, even after a reminder, did not return the main questionnaire, received a one-page questionnaire 12 to 16 weeks after the mailing of the main study.

Measurement instrument: The questionnaire was composed of three parts. The first part included questions similar to the main questionnaire on the respondents' age, sex, religious affiliation, specialty and number of assisted terminal patients during the last 12 months. In the second part the reasons for not having participated in the main study were asked. In addition to five given answers ("no time", "did not receive the questionnaire", "not interested in this subject", "worries about the anonymity" and "addressed physician not working here anymore"), an open-ended question asking for other reasons was added. In the third part, three of the 14 statements from the main questionnaire assessing attitudes towards end of life decisions (Miccinesi et al. 2005) were included: 1. "Physicians should comply with a patient's request to withhold or withdraw life-sustaining treatment", 2. "In all circumstances physicians should aim at preserving the lives of their patients, even if patients ask for the hastening of the end of their lives" and 3. "The use of drugs in lethal doses on the explicit request of the patient is acceptable for patients with a terminal illness with extreme uncontrollable pain". The agreement with each statement was measured on a 5-point scale ("strongly agree", "agree", "neutral", "disagree" and "strongly disagree"). The first item assesses attitudes towards non-treatment decisions, the second one attitudes towards the Hippocratic oath ("life preserving") and the third one attitudes towards euthanasia.

Statistical analyses: For statistical analysis STATA 8 was used (STATA Corporation 2003). "Survey"-commands were applied to include strata and weights. For strata the variable "specialty" was set; weights were attributed according to the sample fraction of each "specialty" per country.

As previous studies show that different factors influence attitudes towards end-of-life decisions, e. g. culture and physicians' characteristics (Anderson & Caddell 1993; Emanuel et al. 1996; Hinkka et al. 2002; Rebagliato et al. 2000; Vincent 1999; Voltz et al. 1998;) multinomial logistic regression

analysis was used to investigate, besides the type of questionnaire (main/non responder), the influence of these potential determinants towards the attitudes items (answer categories: strongly agree/agree – neutral – strongly disagree/disagree). Independent variables were: questionnaire (main/non-responder), country (Denmark, the Netherlands, Sweden, Switzerland), sex (male/female), age (>50 years/<50 years), number of terminal patients (0 patients/>0 patients) and religious affiliation (roman catholic, protestant, other religion, no religion, no philosophy of life). As a high correlation existed between specialty and number of treated terminally ill patients, the variable "specialty" had to be excluded from the analysis.

Results

Response rate

The response rates of the non-responder questionnaire ranged from 12.8 % in the Netherlands to 39.4 % in Switzerland (Tab. 1).

For the following analyses questionnaires were excluded if physicians stated that they were either working in a different specialty from the specialties of our sample, or were currently not working.

Reasons for not having sent back the main questionnaire (Tab. 2)

In Table 2 pre-structured and open answers are combined in six categories. In all four countries the main reason for non-response was lack of time (varying between 45.7 % and 57.7 %). The second most common reason was "dissent of this research" (varying between 19.8 % and 25.2 %, e. g. "not interested in this subject", "questionnaire is too long", "worries about the anonymity"). Less often the physicians reported that they were hardly or never respectively involved with terminal patients (varying between 2.6 % and 11.3 %) or that they had not received the questionnaire of the main study (varying between 2.8 % and 9.3 %). Rarely mentioned reasons

Table 1 Total number of physicians/sample size and responders for main and non-response questionnaires (non-practising physicians are included)

Country	Denmark	The Netherlands	Sweden	Switzerland	all four countries
total number of physicians	7 883	14 274	13 892	7 896	43 945
Sample	1 870	2 390	2 642	2 235	9 137
Responders to main questionnaire	1 284 (68.7 %)	1 390 (58.2 %)	1 646 (62.3 %)	1 449 (64.8 %)	5 768 (63.1 %)
Responders to non-response questionnaire	214 (36.5 %)	128 (12.8 %)	343 (34.4 %)	310 (39.4 %)	995 (29.5 %)
Total number of responders	1 498 (80.0 %)	1 518 (63.5 %)	1 988 (75.2 %)	1 759 (78.7 %)	6 763 (74.0 %)

Table 2 Reasons for not having sent back the main questionnaire: non-responder questionnaire – weighted percents of all answers

	Denmark	The Netherlands	Sweden	Switzerland	All four countries
Total number of answers	(226)	(138)	(327)	(311)	(1002)
No time	49.3 %	48.1 %	57.7 %	45.7 %	50.7 %
Dissent of this research	20.4 %	25.2 %	22.7 %	19.8 %	21.8 %
Not or rarely working with terminal patients	6.4 %	8.1 %	2.6 %	11.3 %	6.9 %
Not received questionnaire	5.6 %	2.8 %	9.3 %	7.1 %	6.9 %
General dissent of research	7.1 %	7.6 %	0.6 %	5.7 %	4.5 %
Other reasons	11.5 %	8.2 %	8.9 %	10.5 %	9.3 %

Table 3 Demographic characteristics: non-responder and main questionnaire – weighted percentages

Country	Denmark		Netherlands		Sweden		Switzerland		All four countries	
	Non-response (193)	main (1217)	Non-response (105)	main (1275)	Non-response (285)	main (1514)	Non-response (283)	main (1397)	Non-response (866)	main (5403)
sex										
male	71.2	72.7	67.4	68.9	63.3	61.8	79.5	80.5	70.2	70.8
p ^a	n.s.		n.s.		n.s.		n.s.		n.s.	
age										
<40 years	3.4	5.3	23.7	21.5	15.9	19.0	11.1	13.8	12.6	15.2
40–50 years	41.5	39.7	33.4	39.4	40.6	30.8	43.0	40.5	40.6	37.4
>50 years	55.1	55.0	42.9	39.1	43.5	50.3	45.9	45.7	46.8	47.4
p ^a	n.s.		n.s.		n.s.		n.s.		n.s.	
religion										
rom.cath.	1.1	0.8	13.3	26.1	2.5	4.7	30.8	30.8	12.1	15.5
protest.	61.4	57.8	30.2	21.6	55.6	53.3	34.2	34.2	47.1	41.8
other rel	1.8	2.1	2.1	2.1	5.6	5.2	3.6	5.9	3.7	3.9
non religious	8.5	9.9	32.5	22.5	15.4	20.7	11.8	10.1	15.1	16.1
no philosophy of life	27.2	29.4	22.0	27.7	20.8	16.0	19.6	19.0	21.9	22.9
p ^a	n.s.		n.s.		n.s.		n.s.		n.s.	
Number of terminal patients treated during the last 12 months										
0	6.1	4.7	18.7	8.3	22.1	21.5	33.1	19.2	21.8	13.9
1–10	69.3	73.0	65.4	68.8	47.4	52.1	57.5	63.1	57.3	63.7
11–20	13.9	10.7	10.1	14.0	17.4	14.9	7.1	11.5	12.5	12.9
21–50	8.3	8.9	5.8	7.6	11.1	9.4	1.7	4.4	6.9	7.6
51–	2.4	2.6	0.0	1.4	2.1	2.1	0.6	1.8	1.4	2.0
p ^a	n.s.		<0.05		n.s.		<0.0001		<0.01	

^a Statistical significance according to design-based Pearson statistics

concerned a general distaste for surveys (varying between 0.6 % and 7.6 %; e. g. “I do not answer surveys” or “I want to be paid for surveys”).

Demographic characteristics and experiences (Tab. 3)

No statistically significant differences were found for sex, age or religious affiliation between non-responders and responders. In the Netherlands and Switzerland and for all four countries together, non-responders had statistically significantly

fewer terminal patients than responders (The Netherlands: non-responders 18.7 % “0 terminal patients”; responders 8.3 % “0 terminal patients”; Switzerland: non-responders 33.1 %; responders: 19.2 %).

Agreement with and ‘neutral’ answers to attitudes items (Tab. 4)

The agreement with the “non-treatment decision” statement was statistically significantly lower among non-responders

Table 4 Agreement with and neutral answers to attitudes-items: non-responder and main questionnaire - weighted percentages, odds ratio and confidence interval

Country	Denmark		Netherlands		Sweden		Switzerland		All four countries	
	Non-response (193)	main (1217)	Non-response (105)	main (1275)	Non-response (285)	main (1514)	Non-response (283)	Main (1397)	Non-response (866)	Main (5403)
<i>"Physicians should comply with a patient's request to withhold or withdraw life-sustaining treatment."</i>										
Agree ^a	93.2	97.1	82.8	91.9	82.6	88.1	90.4	93.7	87.2	92.5
OR (CI)	1.93 (0.36–10.35)		2.61 (0.78–8.71)		1.63 (0.78–3.42)		2.18 (1.12–4.25)		1.99 (1.23–3.22)	
neutral ^b	4.9	1.9	9.1	4.7	7.8	5.7	5.0	4.1	6.5	.2
OR (CI)	0.36 (0.12–1.10)		0.46 (0.16–1.36)		0.68 (0.33–1.41)		0.80 (0.35–1.79)		0.61 (0.39–0.94)	
<i>"In all circumstances physicians should aim at preserving the lives of their patients, even if patients ask for the hastening of the end of their lives."</i>										
agree ^a	20.2	25.7	6.6	5.9	27.4	37.6	4.0	7.2	15.8	19.3
OR (CI)	1.36 (0.80–2.30)		0.77 (0.21–2.87)		1.82 (1.16–2.87)		1.97 (1.04–3.74)		1.28 (0.96–1.73)	
neutral ^b	19.1	17.7	21.6	11.0	20.1	22.7	6.6	11.0	15.8	15.7
OR (CI)	0.73 (0.37–1.43)		0.57 (0.13–2.50)		0.82 (0.46–1.48)		0.91(0.40–2.09)		0.81 (0.55–1.20)	
<i>"The use of drugs in lethal doses on the explicit request of the patient is acceptable for patients with a terminal illness with extreme uncontrollable pain"</i>										
Agree ^a	38.8	60.2	73.5	76.7	15.9	35.0	40.8	56.3	35.8	56.5
OR (CI)	2.51 (1.56–4.05)		1.66 (0.69–4.00)		3.02 (1.82–5.00)		1.89 (1.26–2.83)		2.50 (1.97–3.18)	
neutral ^b	21.3	15.3	7.9	11.6	25.1	21.8	26.1	19.6	22.5	17.2
OR (CI)	0.46 (0.26–0.83)		1.42 (0.44–4.55)		0.39 (0.21–0.72)		0.54 (0.36–0.83)		0.49 (0.36–0.65)	

^a reference group is "disagree"^b reference group is "agree"

than among responders in Switzerland and considering all four countries together. For all the other countries the differences were not statistically significant. 'Neutral' answers towards the "non-treatment decision" statement were statistically significantly higher among non-responders than among responders, considering all four countries together (non-responders: 6.5%; responders: 4.2%).

Statistically significantly lower agreement rates were found among non-responders than among responders for the "life preserving" statement in Sweden (non-responders: 27.4%; responders: 37.6%) and in Switzerland (non-responders: 4.0%; responders: 7.2%). Concerning neutral answers no statistically significant differences existed between responders and non-responders.

Regarding the "euthanasia" item, the agreement rate was lower among non-responders than among responders in all countries, although it was not statistically significant for the Netherlands. The greatest difference was found in Sweden (OR: 3.02, CI: 1.82–4.00). With the exception of the Netherlands, non-responders gave a statistically significantly higher rate of neutral answers than responders in all countries (considering all four countries together: non-responders: 22.5%; responders: 17.2%).

Agreement with attitudes items among non-responders according to the reason for non-participation (Tab. 5)

Statistically significant differences existed between non-responders who indicated that they "did not receive the questionnaire" and the other non-responders concerning the euthanasia item. There were no other statistically significant differences concerning agreement with attitudes items, according to the reason for non-participation.

Determinants of agreement (Tab. 6)

The multivariate analyses show that the independent variable "responders/non-responders" is a relevant determinant of all three attitudes items whereby it is the strongest determinant of the "use of lethal drugs" item. For all three items, the agreement is higher among responders than among non-responders. Furthermore, the results show that attitudes towards end-of-life decisions are influenced by cultural factors as well as by physicians' characteristics.

Determinants of neutral answers (Tab. 7)

'Neutral' answers compared with 'agree' answers towards "life preserving" and "the use of lethal drugs" are significantly higher among non-responders than among responders. For

Table 5 Agreement with attitudes-items among non-responders according to the reason for non-participation – weighted percentages

	Statement 1			Statement 2			Statement 3		
	agree	neutral	disagree	agree	neutral	disagree	agree	neutral	disagree
No time	89.2	5.6	5.2	16.8	15.4	67.8	34.6	22.0	43.4
p ^a	n.s.			n.s.			n.s.		
Dissent of this research	85.9	4.0	10.1	19.7	9.7	70.6	42.7	20.9	36.4
p ^a	n.s.			n.s.			n.s.		
Not or rarely working with terminal patients	87.0	9.5	3.6	6.6	16.6	76.7	45.4	24.7	29.9
p ^a	n.s.			n.s.			n.s.		
Not received questionnaire	90.6	3.1	6.2	12.4	31.4	56.2	31.8	41.3	26.9
p ^a	n.s.			n.s.			<0.05		
General dissent of research	86.5	11.4	2.1	0.0	19.4	80.6	50.6	8.3	41.1
p ^a	n.s.			n.s.			n.s.		

statement 1: "Physicians should comply with a patient's request to withhold or withdraw life-sustaining treatment"

statement 2: "In all circumstances physicians should aim at preserving the lives of their patients, even if patients ask for the hastening of the end of their lives"

statement 3: "The use of drugs in lethal doses on the explicit request of the patient is acceptable for patients with a terminal illness with extreme uncontrollable pain"

^a Statistical significance according to design-based Pearson statistics

Table 6 Determinants of agreement (strongly agree/agree)^a with statements – multinomial logistic regression

	Statement 1		Statement 2		Statement 3	
	OR	CI	OR	CI	OR	CI
Non-responder questionnaire (reference group)						
Main questionnaire	1.98	1.14–3.43	1.70	1.19–2.44	2.44	1.86–3.20
Denmark (reference group)						
The Netherlands	0.24	0.08–0.73	0.13	0.08–0.22	2.66	1.83–3.88
Sweden	0.16	0.58–0.45	2.02	1.55–2.65	0.29	0.22–0.39
Switzerland	0.50	0.17–1.45	0.14	0.10–0.20	0.89	0.66–1.19
Male (reference group)						
female	0.61	0.38–0.99	1.00	0.79–1.28	0.72	0.58–0.90
age						
<50 years (reference group)						
>50 years	0.93	0.60–1.43	1.12	0.89–1.41	0.99	0.81–1.20
0 terminal patients (reference group)						
at least 1 terminal patient	1.55	0.96–2.50	0.86	0.65–1.14	0.59	0.46–0.76
roman catholic (reference group)						
protestant	1.28	0.66–2.49	0.56	0.38–0.82	1.06	0.78–1.44
other religion	0.75	0.28–2.03	0.58	0.29–1.16	1.14	0.68–1.92
non-religious/non phil.	1.43	0.71–2.88	0.37	0.25–0.55	1.86	1.37–2.52

statement 1: "Physicians should comply with a patient's request to withhold or withdraw life-sustaining treatment"

statement 2: "In all circumstances physicians should aim at preserving the lives of their patients, even if patients ask for the hastening of the end of their lives"

statement 3: "The use of drugs in lethal doses on the explicit request of the patient is acceptable for patients with a terminal illness with extreme uncontrollable pain"

^a reference group is "disagree"

Table 7 Determinants of neutral answers towards statements^a – multinomial logistic regression

	Statement 1		Statement 2		Statement 3	
	OR	CI	OR	CI	OR	CI
Non-responder questionnaire (reference group)						
Main questionnaire	0.62	0.37–1.02	0.65	0.42–0.99	0.51	0.37–0.69
Denmark (reference group)						
The Netherlands	2.05	1.06–3.95	3.92	2.16–7.13	0.56	0.38–0.82
Sweden	2.40	1.27–4.55	0.96	0.68–1.36	2.44	1.75–3.39
Switzerland	1.24	0.62–2.47	2.75	1.76–4.30	1.40	1.02–1.93
Male (reference group)						
female	1.18	0.78–1.79	1.20	0.89–1.62	1.13	0.88–1.46
age <50 years (reference group)						
>50 years	0.93	0.63–1.36	1.03	0.78–1.36	0.79	0.63–0.99
0 terminal patients (reference group)						
at least 1 terminal patient	0.58	0.37–0.91	1.43	1.01–2.03	1.10	0.82–1.47
roman catholic (reference group)						
protestant	0.62	0.36–1.08	1.53	0.96–2.43	1.18	0.85–1.64
other religion	0.59	0.28–1.21	1.47	0.68–3.17	1.20	0.71–2.03
non-religious/non phil.	0.49	0.28–0.84	1.56	0.97–2.50	0.90	0.65–1.24

statement 1: "Physicians should comply with a patient's request to withhold or withdraw life-sustaining treatment"

statement 2: "In all circumstances physicians should aim at preserving the lives of their patients, even if patients ask for the hastening of the end of their lives"

statement 3: "The use of drugs in lethal doses on the explicit request of the patient is acceptable for patients with a terminal illness with extreme uncontrollable pain"

^a reference group is "agree"

the non-treatment statements the differences between non-responders and responders are not statistically significant.

Discussion

The findings showed that in our end-of-life decision study socio-demographic distortion is not likely. Furthermore, the results indicate that in the main study physicians who are frequently confronted with dying patients were somewhat overrepresented.

With regard to the attitudes towards end-of-life decisions, the non-responders expressed lower rates of agreement in comparison to the responders for the statements "non-treatment decisions", "euthanasia" and "life preserving". Thus, our results indicate that proponents of non-treatment decisions and of euthanasia are somewhat overrepresented among responders, but so are proponents of preserving life as well. "Supporting life-shortening end-of-life decisions" concurs with "supporting preservation of life in all circumstances" in some cases, which shows that these statements are not the extremes of one scale for all physicians. Thus, bias in attitudes should be considered for each statement separately.

Furthermore, our results indicate that ambiguous attitudes are more common among non-responders than responders, especially relating to euthanasia. This result could be an indication that non-responders did not have a clear attitude towards end-of-life decisions because they had not yet formed an opinion on this subject.

The most common reason for not having participated in the main study was "lack of time". Having no time is probably an easy and safe answer, which may be a substitute for other objections to participating, which are more difficult to explain. The fact that the responses to the three attitudes items did not vary – with one exception – according to the reason for non-participation in the main study supports this conclusion.

Some limitations in our study have to be acknowledged. One limitation is the small response rate of the non-responders, especially for the Netherlands (12.8%). This rate is too low to assume that the group of non-responders is representative of all non-responders. It can be expected that the remaining non-responders may differ from the investigated ones, as in the study by van Goor & Stuiver (1998) which showed – albeit not in the field of end-of-life decisions – that the group of 'hard-core' non-respondents differed from the 'soft-core'

ones. A further limitation is connected with the different composition of the non-responder questionnaire and the questionnaire of the main study: In the methodological literature it is pointed out that the response behaviour can be influenced by the composition of the questionnaires (Tanur 1992). Answers to an identical question may differ depending on what questions and/or comments precede the question concerned. So it can be assumed that the differences of agreement towards the attitudes-item found in logistic regression analysis result from the length and the composition of the main questionnaire in contrast to the non-responder questionnaire. Respondents of the main questionnaire were confronted on five pages with the topic of end-of-life decisions (*vignette cases*) before answering the attitudes-items whereas the respondents of the non-responder questionnaire were not subjected to such a topical prefix. The acceptability of euthanasia and non-treatment as well as "life preserving in all circumstances" may have been increased by the description of possible situations (*vignette cases*) in the main questionnaire. This influence might be stronger for people who were previously less often confronted with this topic.

We conclude that non-participation does cause an overestimation of the number of proponents of life-shortening as well as of life-preserving end-of-life decisions. Therefore, non-responder bias should be considered in the different dimensions of end-of-life decisions ("non-treatment decisions", "euthanasia" and "life preserving") separately. More studies are needed to establish how attitudes towards end-of-life decisions between non-responders and responders differ. The question arises whether it may be more economical and revealing to do an intensive non-response study on a small representative sample of non responders e. g. by telephone. This approach may enable for a high response rate to be achieved and a more intensive investigation of each individual subject to be carried out. As "end-of-life decisions" are a sensitive

subject and some types of end-of-life decisions are punishable, it is very important to ensure anonymity for studies in this field. For these reasons, mail surveys may still be the best procedure for questioning non-responders in sensitive areas.

Conflict of interests

All authors confirm that there are no conflicts of interests.

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Zusammenfassung

Antwortende und Nicht-Antwortende in einer Studie zu medizinischen Entscheidungen am Lebensende in Dänemark, Holland, Schweden und der Schweiz

Fragestellung: Richtung und Ausmaß von Teilnahmeverzerrungen in der Sterbehilfeforschung sollen bestimmt werden.

Methoden: Im Rahmen eines europäischen Forschungsprojektes zu medizinischen Entscheidungen am Lebensende wurde bei Ärztinnen und Ärzten in Dänemark, Holland, Schweden und in der Schweiz eine Non-response Studie durchgeführt. Die Personen wurden nach ihren Einstellungen zu und Erfahrungen mit medizinischen Entscheidungen am Lebensende befragt. Der Rücklauf reichte von 12.8 % in Holland bis zu 39.4 % in der Schweiz. Antwortende (n = 5403) und Nichtantwortende (n = 866) wurden hinsichtlich soziodemographischer Merkmale, Erfahrungen mit sterbenden Patientinnen und Patienten und der Zustimmung zu Einstellungen gegenüber Entscheidungen am Lebensende verglichen. Im Weiteren wurden die Gründe für die Nicht-Teilnahme an der Hauptbefragung untersucht.

Ergebnisse: Nicht-Teilnahme führt zu keinen soziodemographischen Verzerrungen, jedoch betreuten die Nichtantwortenden in Holland, der Schweiz und allen vier Ländern zusammen signifikant weniger sterbende Patientinnen und Patienten als die Antwortenden. Die Zustimmung zu den Statements über aktive Sterbehilfe und über passive Sterbehilfe wie auch zum Statement zur Lebenserhaltung unter allen Umständen fiel unter den Antwortenden signifikant höher aus als unter den Nichtantwortenden. Hinsichtlich der Lebenserhaltung unter allen Umständen sowie der aktiven Sterbehilfe waren neutrale Antworten unter den Nichtantwortenden signifikant häufiger als bei den Antwortenden. Als häufigster Grund für die Nicht-Teilnahme wurde "Zeitmangel" genannt.

Schlussfolgerung: Die Nicht-Teilnahme führt zu einer Überrepräsentation der Befürwortenden sowohl von lebensverkürzenden als auch von lebenserhaltenden Entscheidungen. Nichtantwortende haben häufiger unklare Einstellungen gegenüber Entscheidungen am Lebensende als Antwortende.

Résumé

Répondants et non-répondants dans une étude sur les décisions médicales en fin de vie au Danemark, aux Pays-Bas, en Suède et en Suisse

Objectifs: Déterminer la nature et l'importance de biais de participation dans la recherche sur l'euthanasie.

Méthode: Dans le cadre d'une recherche européenne sur les décisions médicales euthanasiques, une étude des non-réponses a été réalisée auprès de médecins au Danemark, aux Pays-bas, en Suède et en Suisse. Les questions abordaient les attitudes et l'expérience des médecins face à des décisions euthanasiques. Les taux de réponses varient de 12.8 % (Pays-Bas) à 39.4 % (Suisse). Les répondants (n = 5403) et les non-répondants (n = 866) ont été comparés selon leurs caractéristiques socio-démographiques, leurs expériences avec des patients en phase terminale et leurs attitudes face à l'euthanasie. Les raisons d'une non-participation à l'étude ont été analysées.

Résultats: Les non-réponses n'ont pas causé de déformation socio-démographique, cependant la catégorie des non-répondants compte de manière statistiquement significative moins de patients en phase terminale que la catégorie des répondants aux Pays-bas, en Suisse et dans l'ensemble des quatre pays. Le taux d'approbation d'affirmations sur le thème de l'euthanasie active et passive et du maintien de la vie était significativement plus élevé parmi les répondants que parmi les non-répondants. Les réponses neutres sur le thème du maintien de la vie et de l'euthanasie étaient plus souvent apportées par les non-répondants. Le «manque de temps» a été la cause de non-participation la plus souvent invoquée.

Conclusion: La non-participation induit une surestimation des partisans de l'euthanasie, aussi bien que des partisans du maintien de la vie. Plus souvent que les répondants, les non-répondants ont des points de vue ambigus envers les décisions d'euthanasie.

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